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Dementia: look closer

Elizabeth Byrne McCullough and Paula Devine



Liz Cunningham from Belfast, who was diagnosed with Alzheimer's disease when she was 48 years old.

The subject of dementia and our approach to it has been hitting the headlines and hovering in the subtext of a wide range of broadcast and print media in recent years. Hardly a week goes by without a press story about potential cures, lifestyle advice on how to reduce our risk of developing dementia, or a heart rending and compelling account of people who are living with the impact of this complex and terminal disease on their lives.

There are nearly 20,000 people with dementia in Northern Ireland now and many thousands more undertaking a caring role for a person with the condition. Compared to 20 years ago, there is more public awareness of dementia as a health condition, as a health and social care

priority affecting tens of thousands of people in Northern Ireland alone, and something which isn't going away.

There is no doubt that public conversations about dementia and related issues of concern are more audible than ever before. This positive effect has been enhanced tremendously by increased numbers of people with dementia talking publicly about their experience. World class communicators like Terry Pratchett, magnificent actors like Prunella Scales, and extraordinary people like Liz Cunningham from Belfast, have publicly shared their experience of dementia. They continue to do this in ways that help us get past the fear and stigma that are still attached to the condition, and through to the real

person, their individuality and their rights.

This Research Update is based on the findings from the 2014 *Northern Ireland Life and Times (NILT) Survey*, which included a module of questions on dementia, many of which had previously been asked in the 2010 survey. Attitude change is notoriously slow paced and incremental in nature, so it is probably sensible to moderate any unrealistic expectations we might have of a mere four years in this context.

Policy context

Lacklustre implementation of strategic policy has seriously compromised positive outcomes for people with dementia and family carers. When Maria McManus and Paula Devine commented on the 2010 NILT results, the work to produce a dementia strategy for Northern Ireland had been underway for a number of years. However, *Improving Dementia Services: A Regional Strategy* (DHSSPS, 2011) wasn't presented by Health Minister Edwin Poots until November 2011, at which point he expressed his view, albeit reluctantly, that the Strategy could be implemented without benefit of additional funds.

This Strategy included a plan of action to tackle modifiable risks; raise public and professional awareness; promote timely diagnosis; support people with dementia and family carers; and develop mental capacity legislation for Northern Ireland. That's an ambitious project by any standards, but something of a poisoned chalice for the Dementia Strategy Implementation group tasked with realising it within the existing budget. In September 2014, a joint Atlantic Philanthropies and Delivering Social Change dementia initiative invested £6.25million in improving services and promoting greater understanding and awareness of dementia in Northern Ireland.

Other policy developments are also important. Alzheimer's Society supported many of the proposals of *Transforming Your Care* (TYC; DHSSPS, 2013), specifically its emphasis on prevention. However, it was clear from the outset that TYC would require a shift in attitudes, understanding and practice to realise the vision for people living with dementia throughout Northern Ireland. Mental Capacity legislation, which is currently at committee stage in the Assembly, is particularly important to people with dementia. In particular, it can support people to exercise their right to make decisions about their own lives and requires others to comply with its provisions.

So it is timely to take a close look at the NILT data to see how, and if, this policy and media activity around dementia has impacted on public understanding, attitudes and behavior in Northern Ireland.

Public knowledge

In 2010, 45 per cent of NILT respondents stated that they know or knew a person with dementia. This has increased to 61 per cent in 2014, and in both years, there was a strong link to the age of the respondents. In 2014, 39 per cent of 18-24 years olds knew someone with dementia, compared with 69 per cent for those aged 65 or over. However, despite nearly two thirds of people knowing someone with dementia, understanding about the nature of dementia, how it affects a person over time, and the links between lifestyle and risk of developing dementia, is still quite hit and miss. Perhaps this suggests that mixed messages are being communicated.

Two very key characteristics of dementia are that it is a disease of the brain rather than a mental illness, and that it is not a normal part of ageing. These facts, if generally known and clearly understood, could encourage people to seek information and support that is vital to their health and welfare, and to that of family carers. It can be the difference

between getting support that keeps a person independent, well and involved, or slowly isolating them and their family to cope alone.

In 2010, 94 per cent of NILT respondents agreed that dementia is 'a disease of the brain' but this decreased to 87 per cent in 2014. The proportion of NILT respondents thinking that dementia is a normal part of ageing was similar in 2010 and 2014: approximately one in four respondents. This figure is highest among those aged 65 or over – 42 per cent in 2010, and 33 per cent in 2014.

In public health terms it is important that people grasp the facts, recognise symptoms, and take action when they encounter them. This 'hit and miss' understanding is even more evident and damaging in terms of risk factors and the links between diet, exercise, alcohol consumption and smoking (see Table 1). An alarmingly low proportion of people – fewer than 1 in 5 (19%) – are aware that high blood pressure increases your chances of getting dementia. Approximately 1 in 3 (32%) agree that smoking has 'nothing to do with dementia'. This means that nearly seven people in ten don't have a clear grasp of the fact that smoking increases the risk of developing dementia. A similarly high

proportion of respondents (68%) don't recognise or don't understand the links between heavy drinking and dementia. Of particular note is the high proportion of people who 'don't know', ranging from 21 per cent to 36 per cent. For all of the five risk factors, the highest levels of 'don't know' responses are among the youngest (18-24 year olds) and oldest (65 years or over) respondents.

Dementia and rights

A sizeable minority of NILT respondents (39%) feel that 'there is little or no benefit to be gained from telling someone they have dementia' (see Figure 1). If we take this to mean that a diagnosis has been made and information would be withheld from the person with dementia, it is a serious breach of a person's rights. If it is interpreted as there being no point in seeking a diagnosis, it is a serious distortion of the facts. There is abundant evidence that most people wish to know if they have dementia, to get information and support post-diagnosis, and to make decisions about their health and welfare when they have capacity to do so. As with other questions, there is a strong link with age, as 50 per cent of respondents aged 65 or older agree with this statement, compared to 28 per cent of those aged 18-24 years. Moreover, people who

Table 1: Factors increasing risk of dementia

	% strongly agreeing or agreeing	% saying don't know
High blood pressure increases your chances of getting dementia	19	36
Smoking has nothing to do with dementia	32	27
People who drink heavily are more likely to get dementia	32	24
If you eat a healthy diet you are less likely to get dementia	27	22
If one of your parents gets dementia, you are more likely to get it too	33	21

Figure 1: Dementia and rights: % agreeing



know someone with dementia are more likely to agree than those who don't know someone: 43 per cent and 34 per cent respectively.

Alzheimer's Society launched its Right to Know campaign in April 2015. It calls not only for an increase in diagnosis rates, but that a person should have access to a Dementia Support Worker from the point of diagnosis to the end of life. However, it is clear that the benefit of telling someone they have dementia is still not widely appreciated, and that a considerable proportion of the survey population – nearly 4 out of 10 – don't view this from a rights perspective. Related to this, Figure 1 shows that one half of respondents thought that 'other people take over making decisions for people with dementia too much'.

Care

In terms of care for people with dementia, an increasing proportion of respondents believe that 'it is better for people with dementia and their families if they are cared for in a residential unit or a nursing home' (34% in 2010, and 43% in 2014). It is tempting to speculate that this view has gathered public support in a period when provision and quality of domiciliary care has come under scrutiny. Evidence from the *Homecare deficit report* (UKHCA, 2015) states that the exceptionally low average rates paid by Trusts in Northern

Ireland for home care for older people should be a cause for concern. Dementia is a complex condition and although a person's needs in the early stages may be few, and practical or social in nature, they must be provided by a workforce which understands how dementia can affect a person and at an unhurried pace. Rationing of social care, which provides only to those with substantial needs, will not have the preventative effect envisaged by TYC.

There is still a significant 30 per cent of respondents agreeing that 'people who have just been diagnosed with dementia are unable to make decisions about their own care', including 41 per cent of those aged 65 years or more. This suggests a low level of understanding and expectation concerning a person's capacity to make decisions in the early stages of dementia, and even less awareness of policy discussions around the development of the Mental Capacity Bill for Northern Ireland. At several points in this survey there is a definite inclination, in the absence of knowledge and understanding of the condition, to default to command and control- denying information about diagnosis, denying a person's right to make decisions. Indeed, a majority of respondents (64%) agreed with the statement that 'people with dementia are like children and need cared for as you would a child', and this

is highest among the oldest age group (74%). It is also higher among those who know someone with dementia (69%) than among those who don't know someone with the condition (57%).

Support

A range of practical scenarios were presented to NILT respondents to tease out how public knowledge and attitudes translate into action. There is some nuance in the responses, but a high expectation of the support that family and partners 'should' provide, as well as what neighbours are inclined to volunteer. It is interesting that a condition like dementia which is complex, progressive and terminal is still perceived as one where a 'duty to care' may readily fall to individual family members, partners and even to a lesser extent to neighbours.

The first scenario related to Sheila, who is living alone, was recently diagnosed with dementia, and has two grown up children living nearby. In response to the question, 'Should Sheila's children be expected to give most of the regular care and support Sheila needs?', 25 per cent said they 'definitely should' and 45 per cent said they 'probably should'. When asked about their own inclination as neighbours of Sheila's, 28 per cent of respondents were 'very willing' and 49 per cent 'fairly willing' to get involved in helping Sheila.

The second scenario related to Harry, who is 75 years of age and living at home with Margaret, his wife of a similar age. Harry's dementia is fairly advanced, he is very dependent and has unpredictable mood swings. In response to 'Do you think Margaret should be expected to give most of the regular care and support Harry needs?', a modest 13 per cent said 'definitely should' and 25 per cent said 'probably should'. In this scenario as neighbours, 23 per cent of respondents were 'very willing' to get involved in helping and 47 per cent describe their inclination as 'fairly willing'.

Both these responses suggest more appreciation of the impact of dementia

on the person and consequently on family carers. This is particularly so in relation to the potential for the complex and changing needs of a person with dementia to overwhelm someone who is themselves older. This suggests that respondents are mindful of the stress an older partner may feel when caring for a person with dementia. This is backed up by the view of 90 per cent of carers themselves affirming that 'caring for someone with dementia is often very lonely' and that it 'often means your own health suffers' (89%) It may also reflect the fact that as a neighbour, being 'willing' suggests consent, whereas reference to close kin taking on a caring role is framed as a compulsion or a widely held general expectation.

Conclusions

The NILT data show us that an increasing number of people know someone with the dementia, but that public understanding

is still quite shallow. Furthermore, many people don't have a good grasp of the links between diet, exercise, smoking or alcohol consumption and the risk of developing dementia. This highlights the need for public information to be made available to inform, to build understanding of how dementia can affect a person, and to encourage people to seek early medical intervention. In the younger age groups, it would function as a strategic preventative measure and could effect a reduction in projected prevalence within a generation.

Contrary to perceptions evident in a sizeable minority of responses, knowing about dementia and seeking appropriate support can benefit the person with dementia. Timely intervention can slow the progress of the disease, give the person the resources to mitigate some of its effects, and extend the period when the person is as well and independent as possible. Having knowledge and

understanding of dementia benefits both the person with dementia and significant others, and can be the first step to building communities which are more supportive and appreciative of the challenges people with dementia and their families face in their daily lives.

References

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The Northern Ireland Life and Times survey is carried out annually and documents public opinion on a wide range of social issues. In 2014, 1211 adults were interviewed in their own homes. Fieldwork was carried out by Perceptive Insight. The survey is a joint project of the two Northern Ireland universities and aims to provide an independent source of information on what the public thinks about the social issues of the day. Check the web site for more information on the survey findings (www.ark.ac.uk/nilt) or call the survey director on 028 9097 3034 with any queries.

Key points

- 61 % of NILT respondents know or have known someone with dementia
- 87% of NILT respondents know that dementia is a disease of the brain
- 26% respondents still believe dementia is a normal part of ageing
- 68% NILT respondents don't recognise or understand the links between heavy drinking and dementia
- 30% NILT respondents believe that people who have just been diagnosed with dementia are unable to make decisions about their own care

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